

## Summary

Since Kennedy *et al* proposed a change in the UK organ donation law<sup>10</sup> there has been a reluctance to make this leap of faith. All other attempts to make significant impacts into the donor deficit have proved disappointing. It seems likely that we could expect a significantly higher donor rate with presumed consent and that this would be sustained because we would create a default position to donate and produce a more positive attitude to donation. A law change would require huge publicity and educational initiatives, which are likely to increase donation.

The new system would allow families of opted-out patients not to be questioned about donation and would allow presumed consent donors the right to donate without high-level relative refusal. To maximise donation we need to consider other radical proposals such as increasing ITU beds, incentivising hospital trusts and possibly deceased families.

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## Presumed consent for organ donation: a case against

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## Introduction

The number of organ donors in the UK is approximately 13 per million population (PMP) per year and has been gradually reducing for most of the last decade. Attempts have been made by transplant surgeons to improve rates of transplantation by using more marginal donors, splitting livers for two recipients and the increasing use of deceased after-cardiac-death donors; the only success has been with the use of living related transplantation and this is largely confined to the recipients of kidneys. For the majority awaiting solid organ transplantation the number of donated organs remains the limiting factor in the number of transplants performed in the UK.

The UK donation rate is now one of the lowest in the developed world while the US consistently achieves organ donation rates of in excess of 25 PMP and Spain approximately 35 PMP. At the same time the need for solid organ transplantation is growing, with rises in the number of patients on the waiting lists of at least 8% per year. Evidence suggests that the UK population is supportive of organ donation, with 90% in favour during a UK survey carried out in 2003, and there are currently more than 16 million people signed up to the organ donor register.

The UK, however, was not always lagging behind and in 1989 organ donation rates in the UK were leading the world at 16 PMP but between 1989 and 2009 the rates of donation

in the UK have declined while elsewhere in Europe and the rest of the world they have raced ahead.

## US and Spanish approach

The US and Spain have used different approaches to increase their rates of organ donation.

In the US the Surgeon General introduced new legislation on to the US Federal Register that meant that each hospital had a legal duty to identify and refer every potential donor to the organ donor organisation (ODO). Potential donors are identified using clinical triggers that are very often present in patients who are likely to be diagnosed as brain-stem dead (BSD). Hospitals failing to comply are financially penalised. The US already had a well-staffed and extensive network of organ donor coordinators and systems in place to reimburse hospital costs. In addition to the improvement in referral arrangements the ODOs around the US invested heavily in training of coordinators in consent processes that are very specific to families of potential organ donors. The coordinators in the US approach families to obtain consent and this has led to a significant increase in family consent rates.

In 1989 the Spanish government invested heavily in the organisational structure of organ donation. They radically increased the number of donor coordinators and ensured

that every hospital in Spain had its own coordinator. They commenced a continuous BSD audit throughout Spain and invested heavily in education and advertising. In addition they introduced a fee structure to reimburse hospitals that provide organ donors. Over the course of the last 20 years the number of organ donors in Spain has increased from 550 to more than 1,500 per year (similar population to the UK) and these results have been reproduced using this system in Italy.<sup>1</sup>

The Spanish have addressed the family consent rate by adopting a long contact method in which donor coordinators identify potential organ donors at a very early stage (using clinical triggers) and spend a long time getting to know the family of the potential organ donor. Should the patient become BSD they have an established relationship with the family. Data from Spain have suggested that family consent rates are more than doubled when a coordinator is able to spend three or more hours with a family when compared with less than one hour.

### UK potential

UK Transplant (now part of NHS Blood and Transplant) began an audit of all deaths on intensive care units in the UK in 2005. This potential donor audit is ongoing and a report of the first 36 months of data identified a number of areas in which potential donors were 'lost'. The donor transplant coordinators collected the data retrospectively but using the medical records identified 1,777 patients for whom the likely cause of death was BSD but where the patients never had BSD tests performed. In addition they identified a further 383 patients for whom BSD was confirmed but where donation was never considered and 210 patients where BSD had been confirmed but the family were never approached.

This is a total of 2,370 patients (790/year) for whom the family could have had the opportunity to consider organ donation but were denied that opportunity.<sup>2</sup> If all of these patients had been included in the potential pool of organ donors even with current consent rates the rate of organ donation in the UK would be 18 PMP and if family consent rates that are seen in Spain were achieved then the rate of organ donation would have been in excess of 25 PMP.

### Presumed consent

Presumed consent is alternatively known as an 'opt-out' system and means that unless the deceased has expressed a wish in life *not* to be an organ donor then consent will be assumed. This can be divided into what is known as a 'hard opt-out' where the family are not consulted or a 'soft opt-out' when the family's wishes are considered in the same manner as with the current 'opt-in' system.

A number of countries have a system of presumed consent, including Spain, but very few use the system in practice. In Spain presumed consent had been part of statute for 10 years prior to the organisational changes without any effect on rates of donation.<sup>3</sup> The US does not have presumed consent legislation. Both have impressive rates of

organ donation and both have seen a rapid increase in a relatively short period of time. Sweden switched to a presumed consent system in 1996 but continues to have very poor rates of organ donation (10 PMP) and attempts to introduce presumed consent legislation in Brazil and France led to a backlash against organ donation.

The question of whether the UK should change to a system of presumed consent is a finely balanced one, generating impassioned debate and a wide range of opinion. There is no doubt that there is an urgent need to address the poor and reducing rates of organ donation in the UK and superficially several factors support a change in the legislation. The consent rates in the UK are poor when compared with other European countries (approximately 60% compared with over 80% in Spain); however, UK consent rates are actually very similar to those in the US but donation rates in the UK are half that of the US. This implies that there are factors other than consent rates that need addressing in the UK prior to blaming our low rates of organ donation on family consent.<sup>2</sup>

There are no fundamental ethical or legal barriers to introducing soft presumed consent legislation in the UK; however, legal advice has suggested that a hard presumed consent law would open to challenge under the European Convention on Human Rights.

There is a belief among some members of the medical profession that the introduction of presumed consent might damage the relationship of trust between clinicians caring for patients at the end of life and their families (survey of Intensive Care Society members, 2008). There is a possibility that some clinicians could opt out of donation programmes at a time when their support is required to improve rates of organ donation. In addition, evidence from recipients of organs suggests that many need to know that organs had been donated without coercion by the organ donor and his or her family. The families of organ donors usually find great comfort in being an active part of the decision to donate.

The introduction of a system of presumed consent would be highly complex and costly if it were to command the trust of the involved professions and the general public. Every member of the UK public at the time of introduction and moving forward would need to be contacted and offered the choice of opting out. This would require a significant and sustained communication programme and any 'opt-out' register would need a robust IT system to support the process. There are real concerns among the general public about centrally controlled IT registers containing personal information and the introduction of such a personal database at this time is probably ill conceived.<sup>4</sup>

Despite support among the UK population for organ donation an attempt to introduce a system of presumed consent might provoke anti-donation feelings and even active anti-donation campaigning among some vocal groups. This view has been supported by some faith leaders who under the current system support organ donation.<sup>5</sup>

## Conclusion

A hard system of presumed consent would almost certainly lead to an increase in rates of donation but its introduction would be open to challenge. The current opt-in system of either registration on the organ donor register or obtaining consent from the next of kin is actually little different to a system of soft presumed consent. In both cases the families of the deceased are approached to obtain family consent; the only difference is the emphasis of any conversation. While such a system could be introduced the cost would run into many tens of millions of pounds<sup>6</sup> and would run the risk of alienating members of the medical and nursing professions whose support is required to run a donation programme. In addition, there would be a real risk of a backlash from members of the public who currently support organ donation, which could have a negative impact on donation rates.

It seems a little unfair to blame the low rates of organ donation in the UK on the families of the recently deceased<sup>7</sup> when the evidence suggests that there are fundamental problems within the medical profession in the UK. Perhaps it would be sensible to address these issues prior to considering introducing changes in consent legislation and the recommendations of the Organ Donation Taskforce report should go some way to addressing these issues.<sup>8</sup>

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